

Unit 3: Getting People Involved in Research



Topic 3.1: Recruitment: Finding People to be in a Research Study



Main Ideas



- **Recruitment** is the things you do to **find people to be in** a research study.



- To **recruit** people, you might **talk to people at** events, send emails, post on social media, or talk to self-advocacy groups.



Discussion Questions



Finding people to be in a research study



1. How did the Mental Health for All team **help people understand** what their **study is about** and what they would be asked to do?

2. What may **be hard** about **saying no** to:



- A researcher you don't know?
- Your healthcare provider?
- A teacher or service provider?
- A friend?



Discussion Questions



3. What **helped** the Mental Health for All team **make sure** people **knew they could say no** to being in their study?

- **How** can you **help make sure people know they can say no**?



4. What **helped** the Mental Health for All team **develop trust** and **show respect**?

- What can **you do** to help people feel they **can trust** you when you are asking them to be in your research study?



Discussion Questions



5. **How** do you **think** it will **feel** when you ask someone to be in your research study and **they don't want to be in your study?**

- What can you do when that happens?



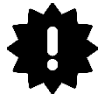
Putting it into Action: Practice Responding to “No”

- **Practice what you will say when someone says they do not want to be in your research study.**



- Write a script to help you know what to say.
- Act it out.

Eligibility Criteria



Main Ideas



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- **Eligibility criteria** are the **characteristics** and **experiences** that people **need to be in a** research **study**.
 - This includes the characteristics and experiences that people must **have** (inclusion criteria) and must **not have** (exclusion criteria) to be in a research study.
 - **Only people** who have **all the characteristics** and **experiences** on the list **can be in the** research **study**. This list is different for every study.
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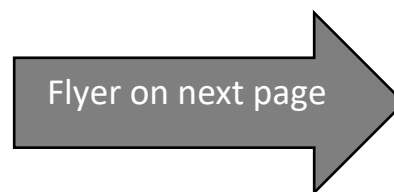
Putting it into action: Recruitment Flyer Search



Review Mental Health for All team's recruitment flyer on the next page.

- **Circle** the part that says what the **study is about**
- **Underline** the part that says **what participants will** be asked to **do**
- **Highlight** the parts that you think **show respect** to people with disabilities. Put a **box** around the parts that **explain who is eligible** to be in the study

Mental Health for All Research team's flyer is on the next page



Do you have a developmental disability? Do you also have a mental health condition?



WE WANT TO LEARN FROM YOU!

What we are doing?

- A research study about whether adding mental health services to support plans helps people get better mental health supports.
- You had mental health support added to your service plan. We want to learn about your new mental health supports.



To be in the study:

- Have a developmental disability.
- Have a mental health condition.
- Be 18 years or older.
- Live in a group home.

Mental Health for All



Mental Health for All is a team of adults with developmental disabilities lead by Ariel and Katie. To learn more

Email:



Call:



What will I be asked to do?

- Participate in a one-hour focus group and a 8 30-minute surveys.
- You can take a break, skip a question, or stop at any time.
- Everything you say is private and confidential (kept secret).
- You can receive up to \$250 for participating in the surveys and focus group.



Note: Materials are for educational purposes only and may not include all required elements.
Citation: McDonald, K. & Schwartz, A. (2023). Research Ethics for All: Accessible Research Ethics Education for Community Research Partners. Syracuse University and Massachusetts General Hospital Institute of Health Professions. www.re4all.org



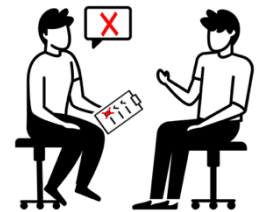
Putting it into Action: Practice Saying No



Practice **telling someone** they are **not eligible** for the Mental Health for All team's research study because they are **too young**.

Write out what you can say about:

- Them **not being able to be in** the study
- The **reasons they cannot be in** the study
- Anything else you might say



Topic 3.2: Finding Research Participants through Other People



Main Ideas



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- Sometimes you need to **ask people** like service providers and family members to **help you find people with disabilities** to be in a research study.
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- You can work with these people to help them understand **why people with disabilities** might **want to be in a research** study and **have the right** to make their **own choices** about being in a research study.
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Discussion Questions



1. **How** did the Mental Health for All team **find people** who might want to be in their research study through **other people**?

- What **made it hard** for them?

- What **helped** them?

Topic 3.3: Consent: Working with People as they Make Decisions about Being in Research

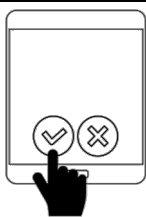
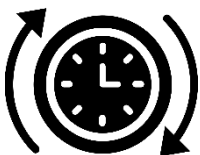


Main Ideas

- **A consent meeting** is when someone **learns about** a research **study** and **decides** whether to be in the study or not.



- Consent must be:
 - **Informed:** people have all the information about the study they need.
 - **Voluntary:** people making their own choice anyone pressuring them.
 - **Ongoing:** people can say no at any time during the study.



- **Giving consent** is when someone **says yes** to being in a study.



- **Dissent** is when someone decides they **do not want** to be in a research **study**.



Discussion Questions

1. What does it mean to be **informed**?



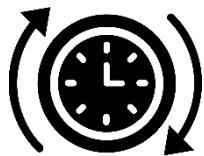
- **What information would you want to know** about a research study before deciding to be in it?



2. What does it mean to make a **voluntary choice**?



Discussion Questions



3. What does it mean that being in a research study is an **ongoing decision**?



4. What are some **signs** that **someone changed their mind** and **does not want to be** in a research study **anymore**?



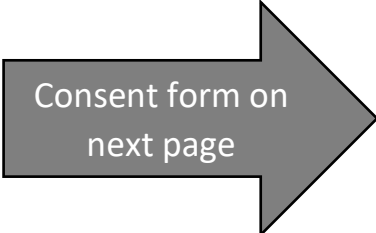
Putting it into Action: Consent Document Search



Consent Document Search

Look at the Mental Health for All team's consent document on the next page.

- Underline where the document explains people's **choices** to say yes (**consent**) or no (**dissent**).
- **Circle** information about **who is doing the study** and how to **contact** the research team.
- **Highlight** information about **why** the research study is being done
- Put a **box** around the parts of the form that tells people **what they will do** if they are in the study.
- **Highlight** information about **risks** and **benefits** of the research study.



Consent form on
next page





Consent and Assent Form

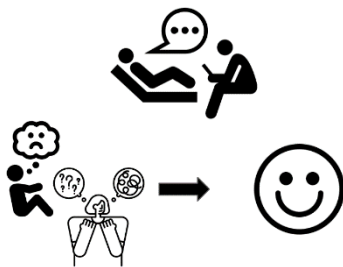
Note: This form is to help people learn about research ethics and not for a real study.

If you are the legally authorized representative for a person who may take part in this study, permission from you is required and the assent (agreement) of your relative or ward is required. When the word “you” appears in the consent form, it refers to the person for whom you are the legally authorized representative.

Principal Investigator: Ariel and Katie

Email  : (email address)

Phone  : (phone number)



You are invited to be in a research study. Many adults with developmental disabilities who live in group homes experience anxiety and depression, but don't get the support they feel they need. We want to learn if adding mental health services to support plans helps people get better support for their mental health.

Mental Health for All is a team of adults with developmental disabilities lead by Ariel and Katie

We are asking you to be in this study because you have important experiences that can help us to understand how adding mental health services to support plans might affect mental health.



This form has **information about being** in this study. If you want to be in the research study, you will sign this form. We will give you a copy of the form to keep.



It is **your choice** whether you want to be in this research study.

What will happen if you decide to participate?

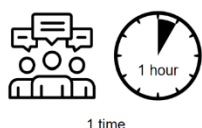
Your service provider is adding mental health services as part of your support plan. This is something that is happening to everyone who has your service provider—even people who are not in the study. We want to know what that change is like for you.

This study has 2 parts:



1. **Surveys:** In an online form, you will answer questions about your experiences with mental health services and your mental health.

We will ask you to complete 8 **surveys at different times**. You will do **1 survey every 3 months**. Each survey will take about **30 minutes**. You will share your experiences with mental health so we can learn more about how mental services may help you feel better.



2. **Focus group:** As an in person group interview with other people who have similar experiences to you, we will ask you questions about your experiences with mental health services.

We will also ask you to be in a **focus group 1 time** at the end of the 2 years. You will be in a focus group with other adults with developmental disabilities who also have depression and anxiety and live in group homes. The focus group will take up to **1 hour**.

There are **no right or wrong answers or experiences**. You are the expert on your experiences and feelings and we want to learn from you.

You can **skip questions** or **stop** whenever you want.



How will we protect your privacy and confidentiality?

We will do the focus group in a place where no one not in the focus group can see or hear what you say.



We will keep what you say confidential (private or secret)

To keep what you say confidential, we will:



- Put a **number** on the information instead of your name.
- **Lock the office** where we keep your information and put **passwords** on all computer files.
- **Not share** your information:
 - with people who are not part of this research study
 - in ways that let other people figure out what you said
 - For other research studies



- **Only share** your information with people who are responsible to make sure that this research study is done correctly.
- **Erase** the file with your name and contact information after 5 years.

If during the research you tell us that **someone is hurting you** or **you are hurting someone**, then we **have to tell someone who can help**.

We have to do this to help make sure **you are safe**.



Will you audio-record me?

If you agree, we will **audio-record** the focus group. The recording will only be used so we can make sure we have good notes about what you said. Only the research team will have the recording. If you do not want to be recorded, we will take notes.



After the focus group, we will **type everything you said** onto a page. We will destroy the recording after we check our notes (no longer than 2 months).



Can anything bad happen to me?



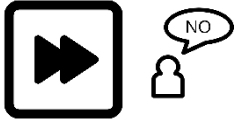
We do not expect anything bad to happen to you from doing the survey and being in the focus group. However, it is possible that you might feel **uncomfortable** thinking about difficult experiences. Or, you might feel **frustrated** if you are not sure how to answer a question.



Sometimes when information is shared or stored online, it can get stolen by people who shouldn't have the information. We will keep information safe by using encryption and passwords, but we cannot promise that someone will not find a way to get to the information.



Other participants may share what you said in the focus group with others. Although we will ask everyone to keep what is said in the room, in the room, we cannot promise that other participants will not share what you said outside of the room.



If you don't want to talk about a topic, you can **skip** the question.

You can always say no to anything in the research.

What will I get from participating? 

You might **like** sharing your ideas. You may **feel good about helping us learn** about how mental health services can help make people feel better.

Will I be paid for being in the study?



You will receive a **gift card** to thank you for being in the study. You can earn up to \$250 for doing the surveys and the focus group for the study.

What should you do now?



Ask questions.



Think about it.



Talk to a friend or family member.




Decide if you want to share your experiences with mental health services in the survey and focus group


If you don't want to be in this study, no one will be upset, and it will not impact your relationship with the university.


Who can I contact if I have questions?

Ariel and Katie are in charge of this study. You can contact them if you have any questions.

Email  : (email address)

If you have questions about your rights when you are doing the focus group or if want to speak with someone who does not work with Ariel and Katie, you can contact the IRB at the University. The IRB is in charge of keeping people safe when they do research.

Phone  : (phone number)

Email  : (email address)

If you would like to participate



Do you understand everything on this form? What questions do you have?

Remember:

- It is your decision whether or not to participate in this study. Your participation is voluntary.
- You may skip and/or refuse to answer any question for any reason.
- You may stop your participation in this study at any time, without anything bad happening.

Saying, “yes, I want to be in the study,” means you would like to volunteer to do this study.

Before you say “yes,” you will be asked to talk about all the things you might do in this study. Saying “yes” means you asked me all the questions you have about this study, and I was able to answer all your questions.

1. Do you agree to let audio-record the study?		Yes ✓ <input type="checkbox"/>	No ✗ <input type="checkbox"/>
2. Do you want us to contact you in the future about other studies?		Yes ✓ <input type="checkbox"/>	No ✗ <input type="checkbox"/>

All of my questions have been answered, I am 18 years of age or older, and by signing this consent form, I agree to participate in this research study. I have received a copy of this form for my personal records.

Participant Name Participant Signature Date

Guardian/Legal Representative Name Guardian/Legal Representative Signature Date

Researcher Name Researcher Signature Date

Topic 3.4: Consent Capacity



Main Ideas



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- **Consent capacity** is someone's **ability** to make their **own decision about** being in **research**.

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- Consent capacity can **change**.
 - **How much consent capacity someone needs** to make their own decision will **depend** on the **bad things** that can happen in the study.



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- We can make **information** about our research more **understandable** so more **people** can **understand** the **good** and **bad** things for themselves about being in a research study.
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Discussion Question

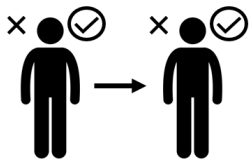


1. **What can you do if you're not sure if someone can make their own decision to be in a research study?**

Topic 3.5: Assent: Working with Guardians and Parents of Children



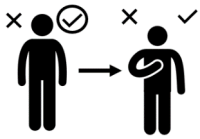
Main ideas



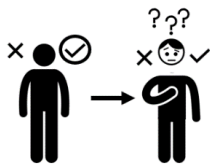
- If someone **does not** have **consent capacity**, they need a **legally authorized representative**, or LAR, to **decide** if they can be in a research study.
- **Assent** is someone with a legally authorized presentative (LAR) **saying** or **showing** with their body that they **want to be in a research** study.



Discussion Questions



1. **How can you help** someone with an LAR **make their own decision?**



2. **What signs might tell you that someone might not be able to make their own decision** about being in a research study?



Putting it into Action: Working with Guardians

Practice what you would do.



A participant has a guardian and uses pictures and body movements to communicate. **They gave assent** to do the study by picking the “yes” picture. **Their guardian wants**



them to do the study. After about 30 minutes of an interview, **you notice** that **they are turning away from you** and **walking around** a lot.



Putting it into Action: Working with Guardians

What would you do?

- **What could you say to the participant to find out what they want and need?**

- **What could you say to the guardian to make sure they understand your job to make sure the participant feels respected and heard?**